

Action magazine



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ovarian. canceraction

We've made this magazine with you in mind so tell us what you think!

0207 380 1730 Info@ovarian.org.uk ovarian.org.uk

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We are proud to be a member of the Fundraising Regulator. We promise that our fundraising is respectful, open and honest.

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Moving forward

Welcome to our summer edition of Action magazine

After what feels like the longest winter, the days are now warm and bright. Lockdown was not easy, but I hope you have now been reunited with your friends and family. It's been almost 18 months since we've been able to see you face-to-face now, and we are still incredibly grateful for your support.

The pandemic has only heightened the need for us to ensure every woman affected by ovarian cancer is diagnosed early and has access to the best possible care. You can find out how our scientists are working on the world's first ovarian cancer screening tool on page six, and how we're helping every woman access the best possible care on page eight.

As shielding has ended, we're winding down our Staying Connected programme. It's been a pleasure getting to know so many of you through our webinars, which are now available to watch on our website's new Video Library. We'll continue to keep you upto-date with the latest Covid-19 news and guidance via our Patient Hub and monthly email newsletter.



And for those who struggle to navigate information online, we're sending out hundreds of our new patient resource packs, created with Ovacome, specifically for those unable to access the information they need about their diagnosis digitally. Featuring handy materials on topics from remote appointments to PARP inhibitors - the new pack will help UK health professionals inform their 'digitally excluded' patients, and is just one step we're taking to support the diverse needs of the ovarian cancer patient community.

Thank you for your unwavering support throughout such a turbulent time. We've been busy, as you'll soon find out, but we couldn't do any of it without you. We cannot improve survival rates for ovarian cancer alone. From our fundraisers to our researchers, awareness-raisers to healthcare professionals, collectively we are powerful, and together we will make a difference.



News in brief

Women diagnosed with advanced ovarian cancer now have access to a life-extending drug

This year we successfully campaigned for the maintenance treatment niraparib to be made immediately available to women with ovarian cancer in both England and Scotland.

We know from our community that it can be an anxious time after initial treatment ends. Now that patients can access maintenance treatments such as niraparib at a much earlier stage of treatment, they can take steps to delay progression of the disease from the start, rather than having to wait for it to recur or progress in order to be eligible. This will have a significant impact on quality of life.

Niraparib, also known as Zejula, is a maintenance treatment; it doesn't cure ovarian cancer but it does prevent its progression. By delaying the spread of the disease, women can feel better and live healthier lives for longer, experiencing reduced symptoms. The increase in time between chemotherapy treatments can also mean fewer trips to hospital to receive treatment. Our Chief Executive Cary Wakefield said the announcement marked a quantum leap for women with advanced ovarian cancer and that for many families this will be life-changing.

"By delaying the spread of the disease, women can feel better and live healthier lives for longer"

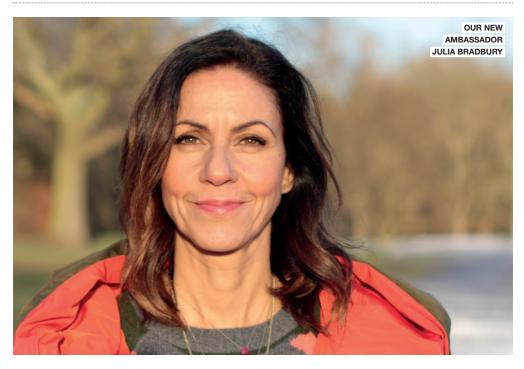
Early detection research

In other news, a 16-year trial at University College London has found that a combination of CA125 blood testing and transvaginal ultrasounds are not viable screening tools to detect earlystage ovarian cancer.

The trial included over 200,000 healthy post-menopausal women from across England, Wales, and Northern Ireland. Our Chief Executive Cary Wakefield said,

"Research showing us what doesn't work is as valuable as showing us what does. While these results are disappointing, they have shown how important further research is to develop a screening tool for the next generation, that detects ovarian cancer at its earliest stages."

Find out how our researchers are progressing towards creating the world's first ovarian cancer screening tool on page six.



Our BBC Lifeline Appeal

Hopefully, you had the chance to watch our BBC Lifeline Appeal that aired on BBC1 and BBC2 back in January. Rosie, Laura and Suzie bravely shared their stories to help viewers understand more about ovarian cancer. Professor lain McNeish, Director of the Ovarian Cancer Action Research Centre, explained how our research will help more women survive the disease.

We are also incredibly grateful to TV presenter Julia Bradbury, of Countryfile and Britain's Best Walks fame, who kindly presented our appeal. Julia shares our passion in challenging the health inequalities that women can face and we're delighted to announce she has joined us as an ambassador.

Julia, said: "Here in the UK, a woman dies of ovarian cancer every two hours.

"Discovering kinder and more effective treatments will transform lives" Ovarian Cancer Action runs innovative public awareness campaigns as well as funding vital research into preventing the disease, diagnosing it as early as possible, and discovering kinder and more effective treatments. Improvements in each of these areas will transform the lives of women today and for generations to come."

You can watch our BBC Lifeline Appeal on our brand new Video Library.

Visit: ovarian.org.uk/videos

Early detection saves lives

Our researchers are determined to develop a screening tool for ovarian cancer

Why we need a screening tool for ovarian cancer

Screening programmes have dramatically improved survival rates for other cancers because they identify cancer early. Early diagnosis makes a huge difference to a woman's chance of surviving ovarian cancer, but the majority are diagnosed late.

The most effective screening tools pick up abnormal cells before they turn cancerous. To achieve this for ovarian cancer, we need to find answers to the missing puzzle pieces that other successful cancer screening tools have.

What are the missing pieces?

To develop a successful cancer screening tool, you need several 'pieces' for it to be effective and safe. If you look at cervical screening, we know:

- The exact location from which the cancer starts
- What happens to turn these cells cancerous, and how long this takes
- A 'marker' of disease to detect cancer, through a blood or tissue sample for example
- And an effective way to treat the pre-cancerous cells that are picked up

We don't have these answers for ovarian cancer.



So what's the plan?

Professor Ahmed Ahmed and his team from the University of Oxford want to find the missing pieces that up until now have prevented the development of a screening tool. They have already found one important piece of the puzzle: the majority of ovarian cancers start in the fallopian tube.

So far they have discovered



BE PART OF SCIENTIFIC BREAKTHROUGHS AND JOIN THE LEAP

When a life-extending drug was recently made available to women with ovarian cancer, our CEO called it a "quantum leap for women". This is the level of progress we must maintain to reach a world where no woman dies of ovarian cancer.

Which is why we have created the Leap, a community who want to change the landscape of ovarian cancer. Your monthly donation will help support research and is a commitment to every woman living with ovarian cancer now and in the future. Join the Leap today at ovarian.org.uk/the-leap

six previously unknown cell types in the fallopian tubes, which relate to six different types of ovarian cancer. This is an important step in identifying the cell of origin in ovarian cancer, and brings us one step closer to finding a way to screen for it. The team is also monitoring the fallopian tubes of women who carry a higher risk of ovarian cancer to try and identify pre-cancerous cells. This has previously been

difficult for researchers, but Ahmed's team is using innovative and novel technology to overcome these barriers.

Where are we now?

The research team are now growing cancer cells in the lab to determine the stages of how these cells turn cancerous. They are also looking at DNA from cancer

and non-cancer individuals to identify the key DNA changes that occur in early ovarian cancer, to try to find markers that could be screened for.

Even though life-changing research takes time and collaboration, Professor Ahmed and his team are already making breakthroughs that will bring us closer to our shared goal of more women surviving ovarian cancer.

Raising the bar for ovarian cancer patients

To transform ovarian cancer survival rates, we have been awarded £1.2 million from the UK Government Tampon Tax Fund

With this funding we will launch our first ever clinical improvement project to establish best practise and ensure every woman across all four nations receives the best possible care.

Building the foundations

Back in 2018, we jointly-funded a pilot that mapped ovarian cancer diagnosis, treatment and survival across England. Audits into other diseases have greatly improved survival rates. So our aim was to gather existing data, prove how useful a full-scale audit would be, and start identifying where improvements need to be made.

Thanks to this work and our ongoing campaign, the Government have just announced that it will fund a full-scale clinical audit into ovarian cancer.

The pilot allowed us to identify regions where women with ovarian cancer are most disadvantaged. Thanks to this funding we

"A woman with ovarian cancer deserves the best chance to survive her disease, no matter what her age is or where she lives. Now is the time for us to take action and ensure that no woman is left behind"

Marie-Claire Platt, Head of Public Affairs and Research



can now begin to work closely with cancer centres within these regions and encourage them to take part in our project. We intend to award funding for up to eight pilot centres to address these inequalities. Each centre can then share their learnings to help others too.

Age inequality

Back in March, we launched the first in a series of reports to highlight the inequalities that exist for women facing an ovarian cancer diagnosis, ranging from their age and ethnicity to where in the country they live.

Over 7,000 women are diagnosed with ovarian cancer each year, with more than a third over the age of 70. Yet our report revealed that women over 70 are

significantly less likely to receive any treatment for their cancer.

Marie-Claire Platt, our Head of Public Affairs and Research, said: "A woman with ovarian cancer deserves the best chance to survive her disease, no matter what her age or where she lives. Now is the time for us to take action and ensure that no woman is left behind."

High-quality care

Pamela Bonati was diagnosed with ovarian cancer at the age of 78. She has received a high-standard of care and her experience is an example of the care all women deserve, irrespective of their age. From a swift diagnosis to being offered a combination of surgery and chemotherapy to treat the disease.

Pamela is currently undergoing a treatment that she is able to take from home, with minimal hospital visits, and describes life as normal, relatively speaking.

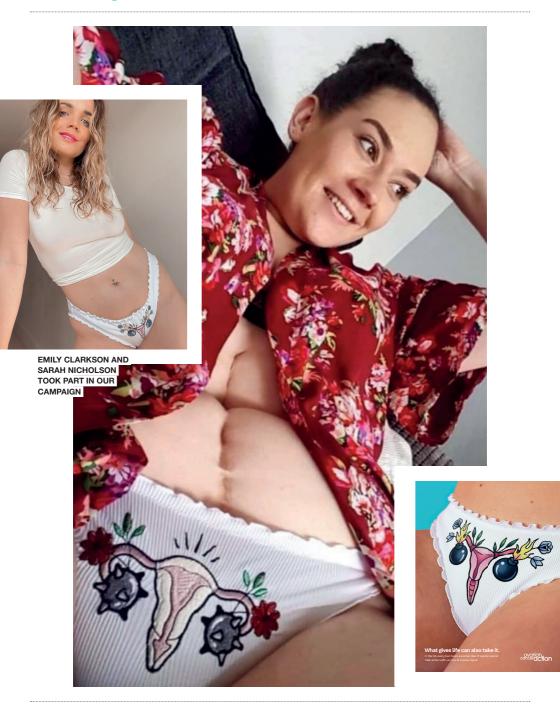
"I have my ups and downs but generally fare well" shares Pamela. "Before my diagnosis I was swimming, walking and travelling at every opportunity and I hope to be back doing those things again eventually. I'm very grateful for the excellent treatment I have received and the time it gives me with my rock of a husband, my son and his wife and our wonderful friends. I sincerely hope I have a lot more living to do."

JOIN OUR MOVEMENT

To be the first to receive the next in our series of reports, as well as the very latest updates on the research you've helped to fund, sign up to our newsletter at:

ovarian.org.uk/stayintouch

Action magazine



#PoseInYourPants

World Ovarian Cancer Day took place on May 8th. We joined forces with 15 social media influencers to get the nation's eyes on ovarian cancer

Although five-year survival rates for ovarian cancer are improving, they are still worse than other cancer survival rates, such as breast cancer, were two generations ago.

We need better awareness, better diagnosis and better treatments to help more women survive this disease.

But for too long, ovarian cancer has gone unnoticed. So we thought it was time to shake things up.

We joined forces with 15 social media influencers to showcase a range of specially designed underwear that demonstrated the power of ovaries, and the destruction that ovarian cancer can cause.

The knickers featured embroideries of the female reproductive system

illustrated with striking images of bombs and grenades, juxtaposing the life-giving power that ovaries possess with the potential deadliness of ovarian cancer.

The influencers posted photos of their specially designed pants on their social media, with messaging around ovarian cancer. Influencers included our incredible ambassador Julia Bradbury, Emily Clarkson, Georgina Horne, and Sarah Nicholson.

Using the hashtag #PoseInMyPants, people were directed to our website to read more about how our research and awareness work, and how they could get involved.

We also asked you to like, share, and comment so that we could spread our message far and wide, and you did not disappoint.

We are delighted to announce that together we were able to reach 1.9 million people!

Our Chief Executive, Cary Wakefield said: "Survival rates for ovarian cancer belong in the past. This World Ovarian Cancer Day you helped us expose this disease and bring to light the breakthroughs we need to fund to stop it taking the life of one woman every two hours here in the UK."

We'd like to say a huge thank you to our influencer friends for going above and beyond to help us reach more women, and we would also like to thank you, our supporters. Every like, comment, and share helped us raise awareness; we're so grateful to you all.

Walk in Her Name

This March
hundreds of
our supporters
across the UK
joined our Walk
in Her Name
Step Challenge
to help fund
lifesaving
ovarian cancer
research

Throughout March, we challenged you to walk 295,000 steps, one for every woman diagnosed with ovarian cancer globally each year.

We were blown away by your dedication and energy. Within days, our walkers had already exceeded the £29,500 goal and ended the month almost trebling it. Together you walked over 70 million steps, that's over 30,000 miles, and by doing so have raised over £96,000. Thank you to everyone who took part; you're amazing!

Meet Paramjit

Paramjit lost his beloved wife Ravi in May 2017. Since then, he has held awareness talks and taken on multiple fundraising challenges in his passion to help more women survive ovarian cancer.

Paramjit said: "I took part in the Step Challenge in loving memory of my wife and all the women whose lives have been lost by ovarian cancer. In doing this challenge we have not only remembered our loved ones but also raised awareness and vital funds towards lifesaving research to help save more lives."

"Every step taken simply equates to a step closer to early detection which in turn, means more lives saved"





Meet Kizzie

Kizzie sadly lost her mum Kim to ovarian cancer in 2021. Inspired by her mum's positive energy, just two weeks later

she decided to take part in our Walk In Her Name Step Challenge. Kizzie raised a

whopping £3,176, reaching the top of our fundraising leader board. Getting out into nature

and walking really helped Kizzie's mental health. She particularly loved

walking along the

seaside as it was
Kim's favourite
place. Kizzie
said: "Doing
everything I
can to support
Ovarian Cancer

Action means

the world to me and my family. I know that mum would be so proud of everything I have achieved so far."

Meet Jack

11-year-old Jack ran 43 miles throughout February half term. This is the distance from his home to the hospital where his mum was treated for ovarian cancer.



"I knew it would be really hard, but it's just running and I haven't had to go through as much as other people. If it wasn't for people that raise money, the research and medicine might not have been found to help my mum and others like her. So I want to do my bit to help in the fight against this horrible disease"

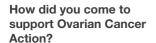
In total Jack has raised an incredible £8,153. Mum Helen is now back at work, running lots and doing well.

TAKE ACTION

Would you like to be a fundraising superstar and take action to help women survive ovarian cancer? To order your free fundraising pack email fundraising@ovarian.org.uk

Five Minutes With...

Duri, Founding Member of our Next Generation Women's Collective.



I lost my mum nine years ago to ovarian cancer, so when I was given the opportunity to support the charity's awareness campaigns at work I was determined to help. I'm the Director of UK Trading at a large media company which means that my colleagues and I can really help get more eyes on ovarian cancer. I was then invited to become a founding member of the



Next Generation Women's Collective, a group of ten businesswomen determined to use their networks to help more women survive ovarian cancer.

You recently starred in the TV show 'DNA: Family Secrets'. Tell us about it. After speaking to Cancer Prevention Officer Jo Stanford about genetic testing, she told me about the show. I was a bit apprehensive at first but I've always been keen to raise awareness of hereditary cancer and in turn, hopefully save lives. You can still catch it on iPlayer!

What do you consider to be your greatest success? My career. Media and specifically trading is dominated by men and to be a woman from a mixed background in this position is a huge achievement for me. From being told that I would need to change my name to succeed or move up, I'm proud to be where I am now. I love being able to use my skill set and network to support OCA.

And greatest failure?

It sounds so clichéd but I believe that you have to fail in order to appreciate your successes. Failure means that you can learn from your mistakes and grow in the future.

What's the best advice you've ever been given? Concentrate on yourself and not on what others think. Be grateful for what you have and not what you don't, as we tend to focus more on this.

Who was your biggest role model growing up?

My mum, she was literally a superwoman.

SNAP POLL

Guilty pleasure: Reality TV

Book: Lean In by Sheryl Sandberg

Shop: ASOS though I have stopped buying clothes! **Relax and unwind:** Going to the gym really helps with my

mental health

Dates for your diary

Women V Cancer's London to Brighton 2021 Saturday 2 October 2021

Cycle from London to Brighton to celebrate Women V Cancer's 10th anniversary. And for one event only, men are welcome too! Setting off from Crystal Palace, cycle through the beautiful surrey countryside to the famous Brighton Pier.

Great North Run 2021

12 September 2021

Join the world's biggest and best half-marathon famous for its warm North East welcome and unbeatable atmosphere.

Royal Parks Half Marathon 10 October 2021

This stunning central London Half Marathon, takes in some



of the capital's world-famous landmarks on closed roads, and four of London's Royal Parks - Hyde Park, Green Park, St James's Park and Kensington Gardens.

Women V Cancer's Ride the Night

Saturday 30 April 2022

Ride the Night is back for 2022, and it will be bigger and better.

Join thousands of amazing ladies cycling 100kms around London at night on Women V Cancer's flagship challenge.

Organise your own challenge

As we slowly get back to normal, organised events are still limited in their availability and capacity. If you want to take part in a challenge but can't find one near you, why not set your own. Walk, cycle, run, jump or skip. Set your own target, tell your friends and family and start fundraising.

For help to get started, or to order a fundraising pack, email fundraising@ ovarian.org.uk



483 Green Lanes, London, N13 4BS Charity registered in England & Wales (No. 1109743) & Scotland (No. SC043478) Inclusion in the Ovarian Cancer Action newsletter does not imply endorsement of a participating organisation or its products.



Are you ready for the UK's biggest women-only cycling event?

Starting at Royal Windsor Racecourse, Cycle 50km or 100km through London at night to raise funds for Breast Cancer Now, Jo's Cervical Cancer Trust and Ovarian Cancer Action.

For more information and to register online:

www.dream-challenges.com

01590 646410 //events@dream-challenges.com

BREAST NOW The research

lo's cervical

To take part you need to pay a registration fee of £45 and fundraise £100 for the Women V Cancer charities. Registered Charity Nos. Breast Cancer Now: 1160558/SC045584, Ovarian Cancer Action: 1109743/SC043478 Jo's Cervical Cancer Trust: 1133542/SC041236. Women V Cancer is established under Giving Works. Registered Charity No. 1078770.

